

When Cancer Happens



**A reference tool for
school professionals**

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What is Gilda's Club Westchester?

Gilda's Club Westchester is a FREE cancer support community for men, women, and children touched by cancer in any way.

Gilda's Club Mission

Our Mission is to create welcoming communities of free support for everyone living with cancer – men, women, teens and children – along with their families and friends. Our innovative Program is an essential compliment to medical care, providing networking and support groups, workshops, education and social activities.

When Cancer Happens – A Resource for School Professionals

"When Cancer Happens – A Resource for School Professionals" is for any school professional who knows a child impacted by cancer.

- Teachers
- Social Workers
- School Psychologists
- Nurses
- Administrators
- Coaches

The following information will help school professionals to support:

- Students who are living with cancer or are post-treatment, as well as their families.
- Students who have a family member or friend living with cancer.
- Students who have a family member or friend who has died from cancer.



Children, Teens and Families at Gilda's Club Westchester

Children

Noogieland holds a unique place at Gilda's Club in that it has two functions: it is both the name of the space in the clubhouse specifically for children, as well as the name of the children's program.

- ✓ Noogie Nights: A weekly on-going activity based group for children ages 5-12 touched by cancer in any way. This group is fun and engaging, while also being a comfortable place for kids to talk about cancer.
- ✓ Kid Support: A 7 week peer support group for children with a family member with cancer and children who themselves have cancer. There are two age tracks (ages 4-7 and 8-12) with content and activities developmentally appropriate for each age group.
- ✓ Kid's Bereavement Group: A 7 week peer support group for children ages 5-12 who have had a family member die from cancer. Content and activities will focus specifically on themes surrounding bereavement.

Teens

- ✓ Tween Time: A monthly on-going activity based group for girls ages 11-16 touched by cancer. Every month the tweens gather to eat dinner, socialize, and if they would like, talk about what it is like to be impacted by cancer.
- ✓ Youth Committee: A volunteer group of high school students whose goal is to raise awareness of Gilda's Club Westchester in the community.
- ✓ Teen Essay Contest: An annual essay contest for any high school student impacted by cancer in anyway.

Families

- ✓ Family Time Events: A monthly theme based activity for families touched by cancer in any way. (These events are also open to the public).
- ✓ Children & Families Open House: An evening open house that reviews all of the things available to children, teens and families at Gilda's Club Westchester.

Parents

- ✓ How to Talk to Children and Teens about Cancer: A lecture for any adult who knows a child touched by cancer.
- ✓ Parenting Networking Group: A monthly group for parents of children and teens when cancer is in the family.
- ✓ Parents of Children with Cancer Networking Group: A monthly group for parents of children and teens living with cancer.

(All activities for children, teens and families are subject to change)



Developmental Aspects Children's Experiences with Illness and Death

**It is important to remember that not ALL children are alike. This provides general information on the developmental aspects of a child's understanding of illness and death, and behaviors to expect.*

Infancy-Toddlerhood (0-2 Years)

Understanding of Illness and Death	Reactions/Behaviors to Expect	Helpful Responses
<ul style="list-style-type: none">▪ No cognitive understanding of illness or death.▪ Sense changes in environment, routine, and the people around them.▪ Aware of changes in behavior and emotions of others.	<ul style="list-style-type: none">▪ Increased irritability/tantrums.▪ Changes in eating habits.▪ Separation anxiety.	<ul style="list-style-type: none">▪ Maintain consistent routines.▪ Enlist support from trusted family and friends to help care for the child.▪ Show physical support by remaining close or embracing when possible (this is more effective than using words).

Preschool (3-5 Years)

Understanding of Illness and Death	Reactions/Behaviors to Expect	Helpful Responses
<ul style="list-style-type: none">▪ May think death is temporary and the person will return.▪ "Magical Thinking" – may think the illness or death was caused by something the child did or said.▪ May interpret things very literally. Euphemisms for death can be confusing and frightening (i.e. "he went to sleep" or "passed away").	<ul style="list-style-type: none">▪ Regression (bed wetting, thumb sucking, increased clinginess).▪ Repeated questions about the illness or death may or may not occur.▪ Responses may be intermittent, but intense.▪ May insist that the parent who has died be replaced. This is an attempt to restore the family to its prior state.	<ul style="list-style-type: none">▪ Provide information that is simple, clear, and factual.▪ Repeat explanations.▪ Provide opportunities for expression (play, art, etc.).▪ Maintain routines.▪ Provide physical comfort.▪ Allow child to participate in rituals.▪ Emphasize that death is not a form of sleeping. Make sure the child understands that death means the body has completely stopped – the person can not breathe, see, feel, hear, smell, walk, or think.



School Age (6-8 years)

Understanding of Illness and Death	Reactions/Behaviors to Expect	Helpful Responses
<ul style="list-style-type: none"> Can usually understand the difference between a simple and serious illness. Worries about what might happen in the immediate future (generally does not think about long term effects). Wants to know physical details surrounding the illness and death. "Magical Thinking" – may think the illness or death was caused by something the child did or said. Beginning to understand the permanence of death. 	<ul style="list-style-type: none"> May ask questions about the physical aspects of the illness or death. May exhibit heightened state of anxiety. Regression. May try hard to appear the same as usual (express feelings in private). May express anger if normal routine is disrupted. May feel guilt for having feelings of anger, or for wanting to have fun. 	<ul style="list-style-type: none"> Allow for intense feelings while maintaining necessary limits. Answer questions with simple and honest responses. Provide opportunities for expression (play, art, etc.). Maintain routines. Reassure the child that he or she will continue to be cared for. Share with the child some normal feelings when impacted by illness and death (anger, sadness, guilt, etc.). Be sure the child understands the difference between a serious illness like cancer, and the flu or a cold (cancer is NOT contagious). Be a positive model, and show how you express your feelings.

Middle School Age (9-12 years)

Understanding of Illness and Death	Reactions/Behaviors to Expect	Helpful Responses
<ul style="list-style-type: none"> Intellectually understands the meaning and impact of illness, and the reality of death and its consequences. Understands death is inevitable and that everyone dies. The meaning of illness and death is primarily centered on how it affects the child socially. 	<ul style="list-style-type: none"> May try to hide feelings. May focus on how the illness or death has disrupted their life. Fear that others may be sick including themselves. May blame themselves for illness or death. Commonly express sadness and fear as anger. May exhibit physical symptoms (headaches, stomach aches, etc.). Difficulty concentrating. 	<ul style="list-style-type: none"> Create and encourage opportunities for peer support. Protect child from taking on the role of the sick or dead caregiver. Reassure child that they are healthy. Share your own feelings. Share with the child some normal feelings when impacted by illness and death (anger, sadness, guilt, etc.). Be patient – it may take months before a child wishes to talk about the illness or death. Keep communication lines open – always let the child know you are there to talk and answer questions.



Adolescence (13-18 years)

Understanding of Illness and Death	Reactions/Behaviors to Expect	Helpful Responses
<ul style="list-style-type: none">▪ Abstract thinking about illness, mortality, and the meaning of life.▪ Aware that illness can cause death.▪ Understand scientific details of illness.	<ul style="list-style-type: none">▪ Struggles to be independent, yet remain close to parents.▪ Afraid to feel too much or let feelings show.▪ Worried that letting out feelings will cause them to completely breakdown.▪ May direct anger towards family members.	<ul style="list-style-type: none">▪ Encourage them to be with friends and do normal activities.▪ Remain connected and keep communication lines open – always let the child know you are there to talk and answer questions.▪ Be honest about the diagnosis and prognosis. Keep them informed of any changes.▪ Involve them in decision making.▪ Model healthy expression of feelings.▪ Do not put too much responsibility on the teen or make them assume adult roles.



Talking about Tough Stuff

Tips for Professionals when Talking to Kids about Cancer and Death

- ✓ Be honest, and use simple straightforward language.
- ✓ Use the words "cancer" and "death."
- ✓ Allow for a range of emotions. Let kids know it is ok to feel sad, mad, scared, or any other feeling. It is also ok if they do not have these feelings.
- ✓ As professionals in the child's life, it is important to let them know you are available to talk. It can be helpful to offer the child an opportunity to make art or play. These are some of the most common way children express themselves.
- ✓ It is ok if the child does not have a dramatic reaction. Children are resilient, and their emotions often come and go quickly.

Activities you can do with Kids who have a Friend or Classmate who have Experienced the Death of a Loved One.

- ✓ Offer an opportunity for kids to make a card (either individually or as a group) for their friend/peer.
- ✓ Allow the kids to decorate a flower pot with paint or markers. Then plant some flowers in the pot to give their friend/peer. This is especially nice if it is a flower/plant they can eventually plant in the ground at their home.
- ✓ Have to kids pick out a journal to give to their friend/peer.
- ✓ You can also ask the friends/peers if they have any ideas of things they would like to do.



Common Questions Kids Have about Cancer and Death

(and some helpful responses)

Explain that it is always ok to ask questions. You may not always have the answer – and that is ok too. Let them know that you will always try to answer their questions, but there may be some things you don't know either.

Q: What is cancer?

A: Cancer is an illness that starts because abnormal cells in a person's body begin to grow rapidly and out of control. Doctors have different ways of getting rid of cancer. They may remove it in surgery. They may give the person with cancer a medicine called chemotherapy that destroys the cancer cells. They also may have the person with cancer get something called radiation. This is the treatment of cancer with radioactive rays. This is done with a special machine made just for cancer treatment.

*It can also be helpful to explain any side effects of the cancer or treatment (hair loss, lack of energy, nausea, moodiness, etc.)

Q: Can I catch cancer?

A: Cancer is not like a cold or the flu. It is NOT contagious, so it can not spread from one person to another and you can NOT catch it. It is ok to hug, kiss, and be close to the person in your life who has cancer.



Common Questions Continued...

Q: Do people with cancer die?

A: Cancer is a very serious illness with many different kinds of treatments and medicine. Many times the medicines and treatments can destroy the cancer, but sometimes they can not. Sometimes people do die from cancer.

* It is important to explain the cancer treatments their family member is going through, as well as the side effects that may be a result of the treatment.

Q: Is it my fault?

A: You did not cause the cancer/death. Cancer/death can not be caused by something you thought, said, or did to another person.

Q: What will happen to me if the person in my life dies?

A: Someone will always be there to take care of you.

* Give examples of realistic family members and friends.



When a Student is Diagnosed

When a student is diagnosed with cancer, their experience in school is impacted greatly. Here is some information that may be helpful to school professionals working with that student, and their peers.

Common Childhood Cancers & Treatments

- Leukemia is the most common type of childhood cancer, although it is possible for children to get tumors in other parts of the body.
- Surgery, radiation, chemotherapy and stem cell transplants are all common treatments for children with a cancer diagnosis.
- The majority of children diagnosed with cancer will be treated and become long term survivors.

The Impact of Cancer & Treatments

Childhood cancer survivors may face years of illness, treatments, and post treatment adjustments. All of these can greatly impact their educational experience.

- Short Term Effects:
 - Physical: hair loss, low blood count, anemia, fatigue, mouth and throat sores
 - Social/Emotional: anxiety, depression, anger, isolation
- Late Effects (may appear months or years after treatment):
 - Physical: vision/hearing loss, thyroid problems
 - Psychological: PTSD, social problems
 - Cognitive: math, problem solving, social skills, handwriting, memory, planning, reading, spelling, organization, processing, concentration.

Re-entry in School

School can bring back normalcy to a child who has been going through a cancer experience.

- Communicate:
 - Appoint a school liaison who will be in contact with the family.
 - Learn about the cancer and treatment, as well as how those may affect the child in the classroom.
- Assess:
 - Evaluate the child's medical needs, academic strengths and needs, as well as psychological strengths and needs.



- Examine School Policies:
 - Certain policies may greatly impact the student living with cancer (physical education requirement, no hat policy, the amount of time allowed between class periods, etc)

Setting the Student up for Success

- Emphasize quality verses quantity in school work
- Shorten assignments/lengthen amount of time for task
- Provide tutoring
- Allow for oral rather than written tests
- Provide homework diary
- Check in regularly
- Provide a convenient locker
- Help classmates to understand (see below)

Helping Classmates Understand

Gaining the support and acceptance of peers is critical to the child's successful re-entry to school.

- The child and family should decide what information can be shared
- Provide information on cancer in general, treatments and side effects, myths about cancer, and ways students can support the student.



Glossary

from *When a Parent Has Cancer:*

A Guide to Caring for Your Children by Wendy Schlessel Harpham, M.D.

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Below is a glossary of cancer-related medical terms, explained in kid-friendly language. Use it as a resource when trying to answer your children's questions or explain medical terms. Definitions are accompanied by analogies, examples, and suggestions for demonstration techniques that may help you clarify meanings. I discourage you from trying to teach children everything in the list, unless they ask to learn it all.

Your children may get frustrated when they can't grasp what you are trying to say despite your many heroic attempts. If you appear calm, it will be easier to reassure them that they don't need to understand everything right away. Let them know that this information is complicated and is hard for you to learn, too. Often they just need more time before the definitions begin to make sense.

Your using the words in conversation will help them, just as it does when learning a foreign language. Be aware that your children may overhear adults talking who are misusing medical terms, or speaking in more ominous tones than necessary. In addition, your children may use a word appropriately, and appear to have a good understanding of its meaning, when in fact their definition may be a little off, or even completely wrong.

Anemia (a-nee'-mee-a)—Someone who has anemia has too few red blood cells. Anemia makes a person feel weak and tired. You cannot catch anemia. Anemia can develop if a person doesn't have enough iron, in which case iron pills will fix it. Bleeding also causes anemia. Many cancer patients who have anemia are not helped by iron pills because their bodies can't make new blood cells very well. If the anemia gets bad, the doctors can fix it by giving blood to the person with anemia.

Biopsy (bye'-op-see)—A biopsy is when doctors remove a little piece of the body where they think there might be cancer. Sometimes doctors can get the piece with a needle that they stick through the skin. Other times they have to do a small operation to get the piece out of the body. Doctors take the little piece that they think might be cancer, and look at it through a machine called a microscope.

Blood counts—Blood looks red when we cut ourselves, but it is really a mixture of things with different shapes and colors floating in salty water. Some of these different things are called red cells, white cells, and platelets. Blood counts tell us the number of red cells, the number of white cells, and the number of platelets in a certain amount of blood.



-Low blood counts—There are not as many shapes and colors in the blood as normal.

-Normal blood counts—The blood is normal.

-High blood counts—Some people say "high" when the blood counts are *too* high, but some people say "high" when the blood counts are normal. Make sure that you and your children understand what you mean when you refer to high counts.

Take a tall clear glass or tube and a bag of colored macaroni. In a bowl mix lots of red macaroni, a few pieces of white macaroni, and a few pieces of another color macaroni. You can use marbles or colored Legos, or whatever else you have available. Call the red item the red blood cells, the white or yellow item the white cells, and the remaining items the platelets. Put the mixture into the glass or tube. Show the children how, from a distance, the tube looks red even though it's a mixture of different colors. That's why blood looks red even though it's a mixture of different colors. There are many more red cells than white cells in the blood. You can use this model to demonstrate anemia by taking out some of the red macaroni; low white counts by removing the yellow macaroni; and so on.

Bone marrow—The red stuff in the middle of bones is called the bone marrow. This is where blood is made. Then the blood goes out of the bone marrow and travels in the veins and arteries to the rest of the body. The marrow is like a car factory, only instead of making cars it makes blood cells.

Take a bone, such as a big chicken bone. Break it in half and show the children the dark red stuff in the middle of the bone.

Bone marrow transplant—There is a kind of cancer treatment where the doctors give a lot more medicine to kill the cancer than they give with regular (standard) chemotherapy. The medicine is so strong that it also kills the healthy blood-making cells in the bone marrow. So, after the medicine kills the bad cancer and the good marrow, the doctors give the person new bone marrow cells. They do this by dripping the new marrow into the sick person's blood through an IV. After a while, the new cells find their new home in the empty bone marrow and begin to make new, healthy blood.

If the new bone marrow is from someone who is healthy and has never had cancer, the transplant is called an allogeneic (al"-o-je-ne'ik) or allogenic (al"-o-je-ne'-ic) transplant. The person who gives the healthy bone marrow is called a donor.

Sometimes the new marrow is taken from the person with cancer. To do this, the doctors first remove the marrow. Then they give the person medicines to get rid of cancer in the body, and they also put medicines in the marrow that they removed. This way, they kill all the cancer in the marrow before giving it back to the person. This type of bone marrow transplant is called an autologous (aw-tol'-o-gus) transplant.



Cancer—Cancer is a disease where a tiny part of the body doesn't work right anymore, and it grows too fast and too much. The growing cancer hurts the healthy part of the person's body. You cannot catch cancer from someone else.

Carcinoma (car'-sin-oh'-ma)—A carcinoma is a cancer that begins in the lining of an organ. It is a type of cancer, in the same way a poodle is a type of dog, roller-skating is a type of sport, and a shirt is a type of clothing. Use these analogies to help you explain how all carcinomas are similar (they are all cancer; they all cause trouble if they are not controlled; they can all be treated) yet everyone's cancer is unique (your poodle may look like someone else's, but you can tell your poodle from every other poodle in the world).

CAT scan—A CAT scan, also called a CT scan, is a picture of the inside of your body. CAT scans have nothing to do with cats or kittens. A regular camera takes pictures of the outside of your body. A CAT scanner takes pictures through the skin. It does not hurt to have a CAT scan done, but since the person has to hold very still during the CAT scan, some people feel stiff and tired afterwards.

Cells (sells)—Cells are tiny parts of the body, so small that you can't see them with your eyes, that work together to make the whole body. If you made a big castle with Legos or building blocks, each piece would be like one cell, and the castle would be like the whole person.

Checkup—A visit to the doctor to make sure that treatments are working, or to make sure that everything is still OK after treatments are over, is called a checkup.

Chemotherapy (kee-moh'-ther-a-pee)—This is special medicine whose job is to get rid of cancer. Some chemotherapy comes in pills or juice and can be taken by mouth. Some chemotherapy has to be put into the blood through the hand or arm or through a tube in the chest. The nickname for chemotherapy is "chemo."

Clinic (klin'-ick)—A clinic is a special place where doctors and nurses help people get well and feel better, and the people go home again after they are treated. At a cancer clinic, all the people they take care of have cancer.

Cured—When the cancer is all gone and is expected to stay away for the rest of the person's life, the person is said to be cured. Sometimes the doctors have to wait until the cancer is gone for a few years before they can use the word "cured."



Diagnosis (dye-ahg-no'-sis)—A diagnosis gives the name of a person's sickness.

Here is an idea to help older children understand the concept of making a diagnosis. Play a game similar to Twenty Questions, where you or your child have to figure out "the

diagnosis." For example, your child can pretend to have a broken bone, strep throat, or poison ivy. You can ask questions like "Does it itch?" (no) "Does it cause vomiting?" (no)

"Does it hurt?" (yes) "Are you sick all over or just in one place?" (just in one place) and so on. When you can name the medical problem, you have made the diagnosis and won the game.

With younger kids, it may work better if you stay away from medical diagnoses. For instance, you can play a game where the child tries to figure out what is in a paper bag. Use an apple or a stuffed animal. Let them ask questions. Let them touch it through the paper bag while you make 'the comparison to your doctors feeling a lump under your skin but being unsure of what it is. When your kids have figured out the identity of the hidden object, they've made the diagnosis.

Drug—A drug is any liquid or pill that you take into your body that changes the way the body works. Drugs can be good or bad depending on how they are used. Doctors give drugs to people with cancer to help get rid of the cancer and to help the person feel better. Point out the difference between drugs used for healing, and street drugs. There is such a big push to sensitize kids to the dangers of drugs with the "Say No to Drugs" campaign that some children may be frightened or confused when you refer to therapeutic drugs.

Fungus (fun'-guss) (the "guss" rhymes with fuss); **fungi** (fun'-ji) (the plural form of fungus)—A fungus is a type of living thing that is like a plant. A mushroom is a fungus. The yeast used to make bread rise is another type of fungus. Most types of fungus do not cause illness, but some can cause sickness if they get into the body. Sometimes a person has to be sick already from a disease like cancer or diabetes before the fungus can make them sick, too.

Hematocrit (hee-mat'-oh-krit)—This is one of the numbers on a blood test result that tells the doctor how much of the blood is red cells.

Hemoglobin (hee'-mow-glow-bin)—Hemoglobin is the stuff in red blood cells that makes them look red. Like hematocrit, this is also one of the numbers on a blood test result that tells the doctor how much of the blood is red cells. It is a different measurement than hematocrit, but the two numbers are related.



Hormone (hor'-moan)—A hormone is a chemical made by the body to help it work right. The body makes many different kinds of hormones. Hormones can also be made by scientists and given like a medicine. Sometimes people with cancer need hormones because the body isn't making the right amount of hormones by itself. Or they may need extra hormones to help them get better.

Immune system—The parts of the body that fight infections and also fight cancer are called the immune system. It may help to visualize the immune system as an army inside of you that gets rid of bad things.

Induction therapy (in-duck'-shun ther'-ah-pee)—The first treatments given to try to get rid of cancer are called induction therapy.

Infection (in-feck'-shun)—When a tiny living thing that is not supposed to be in the body, like a virus, gets into the body, grows, and causes trouble, the trouble is called an infection. The infection can be caused by a virus, bacteria, or a fungus. The infection can be in one place or all over the body. Often people refer to infections as "bugs," as in "I've caught a bug" or "I've got a bug." Make it clear that you are not talking about cockroaches and spiders.

Leukemia (lew-kee'-mee-ah)—This is a type of cancer that starts in the blood.

*See the demonstration described for **Blood counts**. Keep adding white marbles or macaroni to show how the white cells are outnumbering and overcrowding the red cells. You may want to use a different color than white to distinguish the normal white blood cells from cancer cells.*

Localized (low'-kal-ized)—Cancer that is only in one spot and no place else is said to be localized. In a similar way, an infected toenail is a localized infection, and chicken pox is not localized because it is all over the body.

Lumbar puncture (lum'-bar punk'-cher)—See **Spinal tap**.

Lymph nodes (limf nodes)—Everyone has hundreds of little beanshaped bumps called lymph nodes in their bodies. These bumps work hard to fight infection and cancer. For some people, cancer can go to these lymph nodes and make the lymph nodes bigger. Finding big lymph nodes helps the doctor know where the cancer is.

Lymphoma (lim-foe'mah)—This is a type of cancer that starts in a lymph node.



Maintenance therapy (mane'-ten-ants ther'-ah-pee)—After treatments have gotten rid of as much cancer as they can, maintenance therapy is given in hopes of preventing the cancer from coming back if it is gone, or keeping it from getting worse. Some types of cancer need maintenance therapy. Other types of cancer don't because the person does just as well without it.

Mastectomy (mast-eck'-tow-mee)—An operation to remove a person's breast (a lot of people call a breast a boob) is called a mastectomy. This helps the doctors get rid of the breast cancer and prevents it from coming back in the same breast.

Metastasis (met-ass'-tah-sis); metastases (met-ass'-tah-seez) (plural form of metastasis); also called a "met" (plural "mets") – A metastasis is a piece of cancer that broke off from where the cancer started and traveled to a new place in the body where it is growing.

There are innumerable analogies to try. For example, seeds that fall off a tree are like metastases: they are carried in the wind to a distant place where they settle in the ground and sprout into a new tree. Or tell the story of two rabbits on a big island. The rabbits have baby bunnies who leave and settle in a nearby area. After a while, they are old enough to have their own baby bunnies, who move away. Before you know it, there are bunnies living all over the island.

Metastasize (met-ass'-tah-size)—When a piece of cancer breaks off and travels to another part of the body, it is metastasizing.

Nodule (nod-ewel)— This is another word that means lump or bump. A nodule can be cancer, a cyst, an infection, or a lump of fat.

Oncologist (on-kah'-lah-gist)—A doctor who treats only people with cancer is an oncologist.

Oncology (on-kah'-lah-gee)—Oncology is the study of cancer.

Operation (op-er-a'-shun)—When doctors make a cut in the skin to fix something underneath, they are performing an operation. Sometimes people are given medicine to make the part of the body having the operation fall asleep. Then they can't feel any pain when the doctor fixes that part of the body. Sometimes people are given medicine to make them go into a deep sleep during the operation. Then the person can't feel anything at all during the operation. After the doctors fix the problem, they sew the cut together again with stitches. When the cut is all healed, it leaves a scar that you can see on the skin. A scar does not hurt.



Oxygen (ox'-ihjen)—Oxygen is a gas that people need to breathe to stay alive. We breathe air, which has oxygen in it. Sometimes when a person's lungs or heart isn't working well, they need extra oxygen, so they breathe special air from a machine that has more oxygen in it than the air around us.

Platelet (plate'-let)—A platelet is something that is in the blood to help you stop bleeding when you get cut (see **Blood counts**).

Prognosis (prog-no-sis)—The doctors' best guess at how well a sick person will do is called a prognosis. The prognosis gives you some idea of how serious the illness is; it never tells you what is definitely going to happen. No matter what the chances are for getting better, nobody knows for sure what is going to happen. Lots of people who have been told that their prognosis is bad end up doing fine. And sometimes people with a good prognosis get better but then get sick again, or don't get better at all.

Radiation therapy (ray-dee-aye'-shun ther'-ah-pee) (also called radiation)—Radiation is one type of treatment to get rid of cancer. It is done by aiming a special machine at the cancer that hits it with cancer-killing rays. It does not hurt to get radiation, but it does make you tired.

Recurrence (ree-ker'-anse)— Sometimes someone is treated for cancer and the cancer goes away completely for awhile but then comes back. When this happens, the cancer that returns is called a recurrence.

Remission (ree-mish'-on)—After finishing treatment for cancer, if the cancer is completely gone, the person is in complete remission. After finishing treatment for cancer, if there is still some cancer left but it is at least 50 percent gone, the person is in partial remission. Remission is not the same as cure. Remission can last a long time or a short time.

Sarcoma (sar-koh'-mah)—This is a type of cancer that starts in a bone, nerve, muscle, or blood vessel (as opposed to an organ like the liver or lung).

Spinal tap (spi'-nal tap)—This is a procedure in which doctors use a needle to get some fluid from around the nerves in the middle of the back, to find out if there is infection or cancer there. If the doctors find cancer in the fluid, they can sometimes place medicine into the fluid through another spinal tap.

Spleen—The spleen is a part of the body that is inside the belly on the left side, just under the bottom of the ribs. The job of the spleen is to help keep the blood working right and help fight infections. Sometimes cancer can go to the spleen.

Surgery—See **Operation**.



Transfusion (trans-few'-zhun)—When you take blood from healthy people, put it into a special bag, and then drip the blood from the bag into a sick person who needs blood to get better, you are giving a transfusion.

Tumor (tew'-mer)—A lump or bump may be a tumor. It may or may not be cancer.

Viruses (vy'-russes)—Viruses are very tiny living things that are not plants or animals or fungi. They are a kind of germ. They can only stay alive if they are living in other living things, like people. Most viruses do not cause illness. Some cause minor illnesses like colds or warts. Some cause terrible illnesses like polio. Some viruses that don't cause bad sickness in healthy people can make people really sick if the people are already sick from cancer.

X-rays—These are special beams from a machine that can pass through the skin and take pictures of what the body looks like on the inside. The picture is also called an X-ray.



Community Resources

Emotional Support

Gilda's Club Westchester

A FREE cancer support community for men, woman, and children touched by cancer.

80 Maple Avenue

White Plains, NY 10601

Telephone: 914.644.8844

Website: www.gildasclubwestchester.org

SuperSibs

A non-profit organization that provides support for siblings between the ages of 4 and 18 of children with cancer. No fee.

Contact Information:

1566 West Algonquin Road, Suite 224

Hoffman Estates, IL 60195

Telephone: 847.705.SIBS

Toll Free: 866.444.SIBS

Website: www.supersibs.org

L. I. N. K. S.

A free program of Westchester Jewish Community Services. Parents of children with cancer are connected to a trained volunteer, also a parent who has a child with cancer, for support.

Contact Information:

Lenore Rosenbaum, MS

141 Central Avenue

Hartsdale, NY 10530

Telephone: 914.761.0600 x308

Website: www.wjcs.com



Children Living with Illness in the Family (CLIF)

Provides individual and family counseling for children living with cancer in the family. Program for residents of Westchester County. Sliding fee scale based on family income.

Contact Information:

Northern Westchester Guidance Clinic
344 Main Street
Mount Kisco, NY 10549
Telephone: 914.666.4646

Making Headway Foundation

Supportive care for families of children with brain or spinal cord tumors. Monthly support groups for children with cancer, their parents, and siblings. Groups are located in New York City and New Jersey. No fee.

Contact Information:

Edward Manley
Maya Manley
115 King Street
Chappaqua, NY 10514
Telephone: 914.238.8384
Fax: 914.238.1693
Website: www.makingheadway.org

Bereavement Support

The Tree House of the Bereavement Center of Westchester

Provides grief support for children ages 4 to 18 and their surviving parent or guardian. The program is seasonal (Fall, Winter, Spring) and offers an 8-week support group for children who have lost a parent/guardian or sibling. A monthly drop-in group is available to graduates of the 8-week program. The center also offers a school outreach program that includes staff in-services, bereavement groups held within the school setting, student and/or parent workshops, consultations and resource materials. No fee.

Contact Information:

69 Main Street
Tuckahoe, NY 10707
Telephone: 914.961.2818
Website: www.treehouse-bcw.org



The Den

A non-profit support center for grieving children and their families. Offers peer support groups. Children ages 3 to 18 and young adults are grouped according to age and development. Participants take part in writing and art based activities that focus on the safe expression of feelings related to grief. No individual therapy or counseling. No fee.

Contact Information:

Family Centers
48 Arch Street
Greenwich, CT 06830
Telephone: 203.869.4848

The Dougy Center

A non-profit organization located in Portland, Oregon that offers grief support services to children and their families. Through their National Center for Grieving Children and Families, they provide support and training locally, nationally, and internationally to individuals and organizations wishing to assist children in grief.

Contact Information:

3909 SE 52nd Avenue
Portland, OR 97206
Telephone: 503.775.5683
Website: www.dougy.org

The Caring Circle of Hospice Care in Westchester and Putnam

Provides age specific bereavement groups for children and teens. Caregivers groups meet at the same time as kids groups. Groups meet at the Presbyterian Church in Yorktown on Wednesdays or in Yonkers on Thursdays. No fee.

Contact Information:

Hospice Care in Westchester and Putnam
100 South Bedford Road, Floor 3
Mount Kisco, NY 10549
Telephone: 914.666.4228
Fax: 914.666.0378



Hearts & Crafts

Bereavement support groups for children and teens. Each children's support group has a simultaneous parent/guardian support group. Individual counseling is available. No fee.

Contact Information:

60 East Main Street
Ramsey, NJ 07446
Telephone: 201.818.9399
Fax: 201.818.9411

Westchester Jewish Community Services

Offers adult bereavement groups and individual bereavement counseling for children, teens, and adults. Social workers are also available to work with families at end of life. Sliding scale fee.

Contact Information:

Karen Dreher
141 Central Avenue
Hartsdale, NY 10530
Telephone: 914.949.7699 x313

Camps

Hole in the Wall Gang Camp

An overnight camp for children ages 7 to 15 years who have cancer or another serious childhood illness that makes it medically difficult for them to attend other camps. Children go for one of nine week-long sessions. There are camps in Florida, Connecticut, New York, Ireland, and France. No fee.

Contact Information:

565 Ashford Center Road
Ashford, CT 06278
Toll Free Telephone: 800.429.3444
Website: www.holeinthewallgang.org



Happiness is Camping

An overnight camp in New Jersey for children with cancer and their siblings ages 6 to 16. Children can go for one of six 5-7 day sessions. Transportation is provided to and from the New York City office. No fee.

Contact Information:

Attn: Kurt Struver

2169 Grand Concourse

Bronx, NY 10453

Telephone: 718.295.3100

Fax: 718.295.0406

Website: www.happinessiscamping.org

Camp Simcha

Kosher camp for children with cancer and related illnesses. Offers separate 3-week sessions for girls and boys ages 6 to 16. Round trip transportation is provided. Located in Glen Spey, New York. No fee.

Contact Information:

Zahava Farbman, Assistant Camp Director

Chai Lifeline

151 West 30th Street, 3rd Floor

New York, NY 10001

Telephone: 212.465.1300

Toll Free: 800.777.5033

Camp Sunshine

Located in Maine, a week-long camp for children with cancer that offers support for the whole family. There are recreational hours just for the children as well as family activities. Medical facilities and professional staff, food, counseling, and private family suites are provided.

Contact Information:

35 Acadia Road

Casco, ME 04015

Telephone: 207.655.3800

Fax: 207.655.3825

Website: www.campsunshine.org



Ronald McDonald Camp

Residential camp for children ages 7 to 17 with cancer, on or off therapy, and siblings. Junior counseling program for teens ages 18 to 19. No fee for children with cancer; \$100 fee for sibling. There is a limit of one sibling per family. The program is for one week in mid-August.

Contact Information:

Doris M. Sterner, MSW

Camp Administrator

3925 Chestnut Street

Philadelphia, PA 19104

Telephone: 215.387.8406

Website: www.ronaldmcdonaldcamp.org

Information/Education

Children's Brain Tumor Foundation (CBTF)

A nonprofit organization that offers children's support, counseling, information/education, and advocacy services to families and survivors through a free *Resource Guide for Parents of Children with Brain and Spinal Cord Tumors*. Programs include educational conferences, Parent-to-Parent Network, and the Family Outreach Project.

Contact Information:

274 Madison Avenue, Suite 1301

New York, NY 10016

Telephone: 212.448.9494

Toll Free: 866.CBT.HOPE

Fax: 212.448.1022

Website: www.cbtf.org

Candelighters Childhood Cancer Foundation

Offers a youth newsletter and a list of local support groups, camps, brochures, publications, and other information about resources for parents, siblings, long-term childhood cancer survivors and professionals.

Contact Information:

3910 Warren Street

Kensington, MD 20895

Toll Free Telephone: 800.366.2223

Website: www.candelighters.org



American Cancer Society

Provides information about cancer, treatment options, support groups, and general health. Cancer information specialists are available 24 hours a day through the hotline.

Contact Information:

Toll Free Telephone: 800.ACS.2345

Website: www.cancer.org

Websites

www.cancersourcekids.com

For kids 6 to 18 and parents. Provides information about cancer, a question corner, stories and poems, art and games, other teens' stories and advice, as well as a list of wish foundations and cancer camps.

www.grouploop.org

Provides online support to teens with cancer and their parents.

www.encourageonline.org

Provides teens with chronic illnesses support and the ability to read about others' experiences with illness.

www.griefnet.org

Internet community that provides over thirty e-mail support groups. Has moderated chat rooms for kids in grief and parents. Contains lists of books, library information, memorials, newsletters, and suicide prevention.

www.kidsaid.com

Kids and young teens can read about others' experiences with grief as well as post their own artwork and stories and join support groups.

www.kidshealth.org

Information for kids, parents, and teenagers on general health and illness related topics.

www.kidskonnected.org

Provides support and communication between children whose lives have been affected by cancer. Offers a newsletter and other resources.

www.cancerreallysucks.org

An internet-only resource designed for teenagers by teenagers who are impacted by cancer in some way.



www.cancercareforkids.org

Especially for children with a parent, sibling, or other family member who has cancer.

www.kidscope.org

Has special online materials: a comic book for children about chemotherapy and another book about breast cancer in the family.

www.teenslivingwithcancer.org

A wealth of information for teens with cancer including medical facts, social/school issues, nutrition and exercise, and relaxation. Also connects teens thru discussion boards and on-line support groups. With links to additional resources.

Annotated Bibliography

Books for Parents

Babcock, E.N. (1997). *When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients*. Bantam Books.

~See in particular, Chapter 9, "How to Support Your Children When Someone They Love Has Cancer: Sharing the News and Helping Them Understand."

Emswiler, M.A. & Emswiler, J.P. (2000). *Guiding Your Child Through Grief*. Bantam Books.

~Many of the practical suggestions in this book have equal relevance for families dealing with the challenges and changes due to parental illness.

Grollman, E.A. (1991). *Talking About Death: A Dialogue Between Parent and Child*. Beacon.

~A book designed to help parents talk with children about the death of a loved one. Features a read-along story that parents and children can read together as well as a list of resources and related organizations.

Emotional Aspects of Childhood Leukemia: A Handbook for Parents. The Leukemia & Lymphoma Society.

~Contains advice on how to handle the new demands that parents will face, how to talk to children about the diagnosis, and issues relating to the end of treatment. Also includes a list of helpful resources. To obtain a free copy call 1-800-955-4572 or go to www.leukemia-lymphoma.org.



Harpham, W. S. (1997). *When a Parent Has Cancer: A Guide to Caring for Your Children*. Harper Collins.

~Advice on how to approach common problems that may arise when a parent has cancer. Mostly addresses how to care for children under the age of ten but also contains a chapter on teens. Includes a companion book for kids, *Becky and the Worry Cup*.

Heiney, S. P., Hermann, J. F., Bruss, K. V., & Fincannon, J. L. (2001). *Cancer In the Family: Helping Children Cope with a Parent's Illness*. American Cancer Society.

~This book outlines valuable steps necessary to help children understand what happens when a parent has been diagnosed with cancer.

McCue, K. M.A., C.C.L.S. & Bonn, R. (1994). *How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist*. St. Martin's Press.

~Excellent resource for both dual-parent and single-parent families.

Russell, N. (2001). *Can I Still Kiss You?: Answering Children's Questions About Cancer*. Health Communications.

~A question and answer book written by a cancer patient who wrote down the questions he was asked by his children during his cancer experience.

Thirty-five Ways to Help a Grieving Child. (1999). The Dougy Center.

~A guide for caregivers that offers suggestions for how to help grieving children and teens express their feelings. It also provides information on reactions and behaviors to expect from grieving children at different ages.

Books for Professionals

Emily's Story: Back to School After Cancer. Cancervive.

~A 15 minute documentary that follows a 9-year-old girl from her hospitalization to her return to school. It emphasizes the importance of the relationship between patient, hospital, and school. To obtain a copy call 1-800-4-TO-CURE, or go to www.cancervive.org.

Grollman, E. A. (1993). *Straight Talk About Death for Teenagers: How to Cope With Losing Someone You Love*. Beacon.

~A guide that offers advice and addresses issues that teens may have after the death of a loved one such as normal reactions to the shock of death, how to work through grief, and how grief can alter relationships.

Grollman, E. A. (1996). *Bereaved Children & Teens: A Support Guide for Parents and Professionals*. Beacon.

~A guide written by 14 professionals on how to help children and teens through the emotional, religious, physical, and social aspects of experiencing the death of a loved one. Topics include what to say to small children, and how to explain different religious beliefs in words children can understand.



Helping the Grieving Student: A Guide for Teachers. (1998). The Dougy Center.

~A helpful resource for teachers in elementary, middle, and high school that offers tips and information on how to respond to a death.

Keene, N. (2003). *Educating The Child With Cancer: A Guide for Parents and Teachers.* Candlelighters Childhood Cancer Foundation.

~A book that addresses learning issues for children with cancer from infancy to adulthood including education in the hospital and at home, school re-entry, and cognitive, psychological and physical effects of treatment. Also includes a list of resources. Free copies are available for families and teachers with a child with cancer. Call 1-800-366-2223 or go to www.candlelighters.org.

Making the Grade: Back to School After Cancer for Teens. Cancervive.

~An 18 minute documentary that follows three teens on their return to school. To obtain a copy call 1-800-4-TO-CURE or go to www.cancervive.org.

Nessim, S. & Katz, E. R. (2000). *Cancervive Teacher's Guide for Kids with Cancer.*

~A manual for teachers containing information about cancer, treatment, the emotional impact on children, and how to ease the transition back to school. Also includes a list of resources. For a copy call 1-800-4-TO-CURE or go to www.cancervive.org.

Books for Children about Cancer

Ages 3-8

Blake, C., Blanchard, E., & Parkinson, K. (1998). *The Paper Chain.* Health Press.

~An illustrated book that tells the story of how one family coped while their mother was in the hospital during her cancer treatment.

Dodd, M. *Oliver's Story: For Sibs of Kids With Cancer.* Candlelighters Childhood Cancer Foundation.

~Written through the eyes of a six-year-old, this book addresses many questions siblings may have when their brother or sister is diagnosed with cancer. It also provides suggestions for how they can be helpful in the process.

Homer, M. (1999). *Chemo Crusader and the Cancer Fighting Crew.* PEPCO.

~An illustrated book for kids with cancer. It explains cancer and how medicines are used to fight it using simple language easy for very young children to understand.

King, H. E. (1995). *Kemo Shark.* Kidscope, Inc.

~A cartoon illustrated book written by a child psychologist. It features "Kemo" the shark who explains how chemotherapy works to fight cancer.



Kohlenberg, S. (1994). *Sammy's Mommy Has Cancer*. Gareth Stevens Publishing
~An illustrated book for very young children. Follows the story of a toddler whose mom gets diagnosed with cancer. Explains in very simple sentences what cancer is and the treatment that his mom will go through.

Nessim, S., & Wyman, B. *Draw Me A Picture*. Cancervive.
~A coloring/activity book designed to help young children understand what they experience when they have cancer. Marty Bunny becomes sick, is treated, and gets better. To order call 1-800-4-TO-CURE or go to www.cancervive.org.

Numeroff, L., & Harpham, W. (1999). *The Hope Tree: Kids Talk about Breast Cancer*. Simon & Schuster.

~Children of women with breast cancer share their feelings and experiences to help families talk about the difficult issues of breast cancer in healthy ways. Comforting animal characters are used to help make the information more accessible to children.

Ages 9-12

Ackermann, A. & Ackermann, A. (2000). *Our Mom has Cancer*. American Cancer Society.
~An illustrated book written by two sisters about their own experiences when their mother was diagnosed with breast cancer. Gives the perspective of a 9-year-old and an 11-year-old during the process of things such as chemotherapy, hair loss, etc.

Clifford, C. (1998). *Our Family Has Cancer, Too!* University of Minnesota Press.
~A book for families to read together, this book addresses questions that children may have after a parent is diagnosed with cancer. Contains suggestions for how to discuss certain issues as well as a glossary of cancer related terms.

Ganz, P. & Scofield, T. (1996). *Life Isn't Always a Day at the Beach*. Ganz High Five Publishing.

~A cartoon illustrated workbook for kids to color themselves to help them learn and understand their feelings about their parent's cancer.

Hague, M. & Krisher, T. (1992). *Kathy's Hats: A Story of Hope*. Albert Whitman and Company.

~An illustrated book about a 9-year-old girl with cancer. It addresses the feelings of awkwardness and ugliness that occur throughout treatment.



Keene, N. (2002). *Chemo, Crazyiness & Comfort: My Book About Childhood Cancer*. Candlelighters Childhood Cancer Foundation.

~A book that provides clear explanations and practical advice for children with cancer along with warm and funny illustrations to help kids make sense of cancer and treatment. Appropriate for younger children as well, although they may need the help of an adult to read along with them. To obtain a copy call 1-800-366-2223 or go to www.candlelighters.org.

Nessim, S., & Wyman, B. *A Friend For Life*. Cancervive.

~A storybook written to help children understand their illness, treatment, and the changes that will occur in their social and academic lives. To order call 1-800-4-TO-CURE or go to www.cancervive.org.

Richmond, C. (1997). *Chemo Girl: Saving the World One Treatment at a Time*. Jones and Bartlett Publishing.

~Written and illustrated by a 12-year-old cancer patient, depicts Chemo Girl's adventures in saving a little girl from cancer.

Speltz, A. (2003). *The Year My Mother Was Bald*. Magination Press.

~Clare's journal and scrapbook the year her mother is diagnosed with cancer and goes through treatment. Clare tells her story and shares her feelings. Young readers will learn to understand the science of cancer and its treatments and will take comfort in knowing that their feelings are normal and that they are not alone.

Ages 13+

Dorfman, E.V. (1998). *The C-Word: Teenagers and their Families Living with Cancer*. Elena Dorfman.

~Five teens and their families and friends are interviewed on what it has been like for them living with cancer. Many issues such as fears about relationships and chemotherapy are talked about in straightforward fashion.

Fine, J. (1986). *Afraid to Ask: A Book About Cancer*. Lothrop.

~An excellent and highly readable reference volume that includes information about more than 20 specific types of cancer, offered in a question and answer format. Addresses emotional concerns as well as scientific facts. Ages 12 and up.

Gravelle, K., & Bertram, J. (2000). *Teenagers Face to Face with Cancer*. Backprint.com.

~Kids from grade 7 and up describe their treatment and how cancer has affected their lives. The authors provide facts about common teen cancers.

Strauss, L.L. (1988). *Coping When a Parent Has Cancer*. The Rosen Publishing Group.

~Offers suggestions for dealing with the problems teenagers face when a parent has cancer.



Books for Children about Death and Dying

Ages 3-8

Brown, L. K. & Brown, M. (1996). *When Dinosaurs Die: A Guide to Understanding Death*. Little, Brown.

~Addresses in simple language the fears and questions children have about death such as "What does dead mean?" and "Why does someone die?"

Brown, M. (1995). *The Dead Bird*. HarperTrophy.

~A group of children find a dead bird, bury it, and visit and put flowers on the grave everyday.

Cohn, J. & Owens, G. (1987). *I Had a Friend Named Peter: Talking to Children About the Death of a Friend*. William Morrow.

~An illustrated book about a girl whose friend gets hit by a car and dies. Her parents talk to her about things such as what death means, the funeral and burial process, and help her get through her feelings of guilt. This book also provides an introduction that addresses questions parents have about how to talk with their children about death.

Mills, J. (1993). *Gentle Willow: A Story for Children About Dying*. Magination Press.

~In this story, illustrated by Michael Chesworth, Amanda the squirrel calls upon the Tree Wizards of the forest to help Gentle Willow, who is suffering from a mysterious ailment. Amanda experiences emotions common to us all when facing death—loss, confusion, anger, and finally, hope.

Mundy, M. (1998). *Sad Is Not Bad: A Good Grief Guidebook for Children Dealing With Loss*. Abbey Press.

~This guide, which has fourteen sections of two to three paragraphs each, discusses the various aspects of grief, and the ways that people cope with the

death of a loved one. It tells children what they need to know after a loss: that the world is still safe, that life is good, and that hurting hearts do mend. Vocabulary is geared to ages 4-8, but the book is useful for all ages.

Viorst, J. (1971). *The Tenth Good Thing About Barney*. Atheneum.

~A boy's cat dies and he and his family think about ten things they liked about him. Describes in simple language the emotions that the boy goes through after the death of his cat. Also address questions about the finality of death and what happens after death.



Ages 9-12

Anne Frank: The Diary of a Young Girl. (1952). Doubleday.

~A diary kept by a teenager living in hiding in Nazi Germany. It chronicles her experiences for two years ending in her death at a concentration camp.

Brisson, P. (1999). *Sky Memories.* Delacorte.

~An 11-year-old girl recalls and is comforted by the memories she shared with her mother who has died of cancer.

Burnett, F. H. (1987). *A Little Princess.* HarperTrophy.

~A book about what happens to a young girl after her father dies. To help get through hard times at boarding school, the young girl fantasizes that she is a princess.

White, E. B. (1976). *Charlotte's Web.* Harper & Row.

~A pig named Wilbur develops a very special friendship with a spider named Charlotte. Through this very special friendship, the cycle of life and the natural process of death are explored.

Rofes, E. E. (1985). *The Kid's Book About Death and Dying: By and For Kids.* Little Brown & Co.

~Fourteen kids offer facts and advice to help other kids better understand death. Addresses topics such as different funeral customs, death of pets, autopsies, and euthanasia.

Ages 13+

Alcott, L. (1969). *Little Women.* World Publications.

~A story about four sisters growing up in New England in the 1800's. It follows their journey into womanhood through celebrations, family crises, and the death of a loved one.

Fitzgerald, H. (2000). *The Grieving Teen: A Guide for Teenagers and Their Friends.* Fireside, a division of Simon & Schuster.

~The author focuses on the special needs of adolescents, offering clear and concrete help for dealing with a range of difficult emotions and situations, including family changes, issues with friends, and problems at school.

Green, C. (1976). *Beat the Turtle Drum.* Viking.

~A story of how a young girl comes to terms with her sister's death.

Gunther, J. (1949). *Death Be Not Proud.* Harper & Row.

~A true story, told through a father's perspective, about the experience of one seventeen-year-old boy diagnosed with a brain tumor. The story, which ends in the boy's death, focuses on his courage, wit, and uplifting spirit.



Rawls, W. (1984). *Where the Red Fern Grows*. Random House Children's Books.

~A story about a boy and two dogs who become his best friends. They have many adventures together, one of which ends in the death of both dogs. The boy, in his grief, is comforted when he hears the old Native American legend of the red fern that grows over the dogs' graves.

Romain, T. (1999). *What on Earth Do You Do When Someone Dies?* Free Spirit.

~A book that explains in straightforward language what death means, and answers questions that kids may have about death.

For All Ages

Buscaglia, L. (1982). *The Fall of Freddie the Leaf*. Slack.

~A simple story about a leaf that changes with the passing of the seasons and learns that death is a part of life.



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